

Written Public Comments

**IACC Full Committee
Meeting**

May 4, 2009

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John Best

February 5, 2009

Subject: IACC Questions

I'd like to know why you don't just admit the truth, that thimerosal caused all of the autism. Since we have cured lots of kids by removing mercury from their brains with chelation, it should be obvious to you that thimerosal caused the problem.

Do you truly think people are [derogatory language redacted] enough to believe any of the [derogatory language redacted] you try to tell us about vaccines not being responsible for causing this autism horror?

Thank you,
John Best
Londonderry, New Hampshire

Jonathan Sollinger

February 19, 2009

Subject: Autism Initiative

Let's get going on autism research.....

Let us continue to rely on science and compassion to guide as we venture forth to unravel the mysteries of the human brain.

But please, no more wasted time, energy and funding on the pseudo-science blaming the vaccines.

With great respect,

Jonathan Sollinger MD FAAP
Father of a middle son with autism
Office based pediatrician in CT

Willows Pediatrics Group
1563 Post Road East
Westport CT 06880

Note: Personally Identifiable Information (PII) has been redacted in this document

Mark Jones

February 25, 2009

Subject: A Computer-based testing (CBT) system for children for attention deficit hyperactivity disorder (ADHD),Autism,etc We have the support of [PII redacted]

Could you please pass this on to whoever deals with helping children with autism...

I did a PhD to help children which is now called AnimalAgentz.com we have support from United Kingdom and United States of America doctors. Funding has been difficult but more importantly how do I get the press to know about this story, so parents, teachers, doctors know that this exists?

A major London hospital is slowly using our product in a children's Burns Unit. We also have another specialist hospital who is interested in using it for children when they undergo oncology and chemotherapy treatment in the United States.

We are also working alongside a charity to enable children with a short life-span to have a high quality life. We are listed on The National Autistic Society to help children:

<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1404&a=13703>

But Animal Agentz can also be used to just teach basic skills to help children with stress etc. (When they are adults they might not drink/smoke so much etc who knows?)

[PII redacted] wants to put us on TV but is choosing the right time. I have been interviewed on radio (New Zealand etc) and the press (special needs for children, moms blogs). We also now have the support of [PII redacted].

In spite of the above support and others we are still experiencing difficulty sourcing the appropriate level of funding for our project. I would be grateful for any help on how to let more press, parents, teachers and doctors know about Animal Agentz. Do you know any one I should talk to?

How can I improve animal agentz and make more awareness?

I can send you a free log in

Best wishes

Mark

Introduction to web based CBT for children

I would like to tell you about an innovative and interactive web-based product for children, which enables them to better deal with anxiety and stress. It is useful as a relaxation tool and has many applications. It was first developed as a PhD and medical trials were conducted at Great Ormond Street

Children's Hospital in London.

The individual Animal Agentz characters teach children coping skills which range from breathing to self-esteem techniques in stressful times such as first time flying e.g. "Bubbles" the fish can teach many different breathing techniques to relax prior, during or after a stressful event.

In summary Animal Agentz teaches children a good set of skills to cope with stressful situations. Children are therefore better prepared to face a variety of challenging life events.

We have received full support by [PII redacted] at ITV's Morning Show and [PII redacted]. It is successful as a relaxation and coping device and makes it ideal for dealing with children in stressful clinical situations e.g. when they are facing an injection, visit to a dentist, hospital or family doctor. It can also be applied to other conditions such as attention deficit hyperactivity disorder (ADHD), autism and Cystic Fibrosis.

It is also useful in non-medical situations to help calm child down during school examinations, difficult meal times or when shopping and when the child may have a tantrum/naughty behavior, Animal Agentz can help.

If we teach children positive coping skills while they are young, they will be better equipped as young adults to deal with negative issues in a more positive and informed manner.

How does Animal Agentz website work?

Animal Agentz is composed of five animal characters; a fish called "Bubbles" a cat called "Yo-Yo" a dog called "Stretch" a monkey called "Cheiko" and a lion called "Rory".

The individual Animal Agentz characters teach children coping skills which range from breathing to self-esteem techniques in stressful times such as first time flying e.g. "Bubbles" the fish can teach many different breathing techniques to relax prior, during or after a stressful event.

One mother said "If you say to a child 'relax' it means nothing but if you let your child play with Animal Agentz 'fish' (breathing skills) and then say to the child what did the fish do? I then found him acting out the 'fish skills' and becoming relaxed!"

A good example was when my child had a tantrum/ naughty in a shop/school and I said "what does the fish do?" and my child started to breath like the fish skill and calmed down"!

When we recently conducted an independent trial of our product, we found parents had many more applications for which they used Animal Agentz.

The Animal Agentz behaviours are as follows: Breathing skills; taught by a fish Stretching skills; taught by a dog Distraction skills; taught by a cat

Guided imagery skills; taught by a monkey Positive self-statements; taught by a lion The parents applied these behaviours in new ways to help their child. Responses from independent research:

"This is perfect and what me and my family have been waiting years for. My nine year old has A.D.H.D and presents behavioural difficulties.

His biological father rejected him a year ago and this hasn't helped, his self-esteem is very low and finds making new friends very stressful. The local social services tell me he needs therapy like this but are unable to provide it! I am having to pay a private therapist to help my son so when this comes in which I know would benefit many parents that I email, talk to...

Great idea and very user friendly, fab idea and so much needed for the 21st century where many children face daily struggles with little or no help and so they suffer. I am in 100 percent support of this stimulating and so much needed idea!"

[PII redacted], East Yorkshire

"I did these exercises with my daughter; she loved them and wants to play again."

[PII redacted], Plymouth

"This product is excellent and would also be beneficial to children with disorders such as ADHD. It would also be a great intro DVD for children who are about to be admitted to hospital as there was nothing like this about when my son had to go in for a heart op and it would have helped him no end."

[PII redacted], Norwich

"I think it's an extremely good idea."

[PII redacted], Eastbourne

"Whilst doing this survey my son who is 7 and a type 1 diabetic came to watch and listen of his own accord; he really liked it."

[PII redacted], West Midland

"Great idea as it is."

[PII redacted], Lancashire

"I looked at the video with my 6 year old and she loved it."

[PII redacted], Norfolk

"This would be well received in schools."

[PII redacted], Antrim

"Responses from independent research conducted by Mum's Views Ltd" Market Research:
Independent research conducted by Animal Agentz Limited demonstrates parents and their children found our system fun, and easy-to-use for a variety of medical and non-medical issues. Animal Agentz commissioned Mums View Limited who worked with the director of children's marketing at Leapfrog toys Limited. We found children wanting to play with it over and over again.

Animal Agentz has a wider application for non-medical use such as stress management and relaxation. It may also help children who are disruptive and "naughty" to become compliant and happy with many issues.

Research has proved that doctors and other hospital professionals in England and America recommend the use of Animal Agentz to help children with ADHD and autism. The main distribution route is web based via the internet but could be extended to a variety of educational products such as soft toys, books and DVD's.

The research version of Animal Agentz was seen by medical doctors at the American Academy of Paediatrics with great interest (2005/7).

Animal Agentz was demonstrated at the British Medical Association in London and an integrated complementary medical health event in New York, November 2008.

The research has spanned a total of twelve years and is completely novel in its approach. The product has not been produced before because there is a central worldwide market focus on pharmacological drug- based methods and most research is funded by drug companies.

There is a free trial now at the web site www.Animalagentz.com

We are looking for support, funding and awareness.

Dr Mark Jones

Bachelor of Arts (Honors) Master of Arts, Master of Business Administration, PhD

National Endowment for Science Technology and the Arts (NESTA) Fellow Based in London

[PII redacted]

Ellen Boudreau

March 25, 2009

Subject: autism cause - NH - more than coincidence?

I am the 47 year old parent of a 16 year old boy with Asperger's Syndrome, an autism spectrum disorder.

I recently discovered that four of us who lived on end of our street as children are now parents of children on the spectrum. It seems like an unlikely coincidence.

While I contacted our Board of Health, they looked at some of the history of the neighborhood, but didn't interview us. Had they done so, we could have told them of the specifics of what we might have been exposed to while we lived there.

I hope to hear from someone in your office in hopes to help you find a cause for autism and help families like mine.

Sincerely,
Ellen A. Boudreau

Note: Personally Identifiable Information (PII) has been redacted in this document

Donna Oliver

April 10, 2009

Subject: Requesting Information

I recently read the entire IACC Website, as I have a 19 year old with Pervasive Developmental Disorder. I am very interested in panel membership on the Family Advisory Sub-Committee.

As I read the information on the IACC website, I did not see the following addressed at all: Many of our Families have children and adults receiving Medicaid Waivers to cover the expansive needs of our family members qualifying for these services. There is one caveat not mentioned, and it is a huge problem to all of the families receiving services. The Medicaid Waivers literally cannot transfer from State to State. This leaves the families "trapped" in the States where their Waiver was approved. They cannot move to another State without losing their Waiver and being placed on a huge "waiting lists" to obtain waiver services again. I realize Waiver services are both State and federally funded. But there are exceptions, such as Foster and Adoption cases that seem to have the exception to the "waiting lists." I do not feel this at all fair, and needs to be addressed by the IACC along with all of the other current information regarding Autism.

Please let me know if there is a possibility to become involved in the Family Advisory Sub-Committee at this time.

Thank you for your attention to this matter.

Sincerely,

Donna Oliver
Bartlesville, Oklahoma
[PII redacted]

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Eileen Nicole Simon

April 24, 2009

Subject: Comments for the IACC meeting, May 4

The Strategic Plan needs to be updated to include consideration of:

- 1.) Invasive obstetric procedures, induction of labor, Cesarean section, and the current protocol for clamping the umbilical cord within seconds of birth whether or not the infant has begun to breathe.
- 2.) Auditory system impairment as an impediment to learning to speak. A brief lapse in respiration during transition from placental to pulmonary respiration selectively affects the auditory system.

Complications at birth are associated with later development of autism, although epidemiologists make only fleeting mention of how the brain might be affected. All of the evidence regarding umbilical cord clamping indicates that a delay is beneficial. I submitted annotated citations to the literature in previous submissions to the IACC, and posted them at: <http://www.conradsimon.org/IACC.html>

It may prove embarrassing in the long run if obstetrics is not investigated as a possible cause of the increasing prevalence of autism, and if auditory system impairment is not made a priority for investigating the developmental language impairment characteristic of children with autism.

Eileen Nicole Simon, PhD, RN
[PII redacted]

Eileen Nicole Simon

April 29, 2009

Subject: Regarding: Comments for the IACC meeting, May 4

Thanks - can I just add a recommendation for committee members to at least have a look at the following book?

Wagner M. Born in the USA: How a broken maternity system must be fixed to put mothers and infants first. University of California Press, Berkeley, 2006.

If obstetric procedures are safe, they should be able to provide the evidence. Most of the evidence suggests a need for change.

Eileen Nicole Simon

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Amy Brown

April 30, 2009

Brown A, (Department of Complementary and Alternative Medicine) , Roth DE , (Department of Psychiatry, Department of Pediatrics) Sia M, (Department of Pediatrics) Apau-Ludlum N , (Department of Complementary and Alternative Medicine) Davis J . (Clinical Research Center) John A Burns School of Medicine. University of Hawaii, 96813. [PII redacted]
Autism, Diet and Dietary Supplements: A Review.

Background:

Autism is a spectrum of specific disabling medical and behavioral conditions (Autism Spectrum Disorders – ASD) that usually emerges in young children (1 to 3 years of age) with symptoms such as language impairment, decreased eye contact and ability to socialize, repetitive movement, gastrointestinal distress, and possible seizures. The prevalence of autism has soared in industrialized nations to 1 in 150 children with boys three times more likely to be diagnosed than girls. Associations between autism and gastrointestinal symptoms were first reported in the early 1970s - chronic diarrhea, excessive gas, abdominal discomfort, abdominal distension, constipation, and food intolerance. Parents experimenting with diet noticed improvement, yet they were often told no research exists to support the use of diet. Diets reportedly used by parents of autistic children include gluten-free, casein-free, yeast-free, the ecology diet, the specific carbohydrate diet, and others along with various dietary supplements.

PURPOSE:

To review the PubMed literature for evidenced-based research supporting the use of diet and/or dietary supplements in decreasing autism symptoms.

METHODS:

A literature review of PubMed (1953 to February 2009) was conducted using the key words “**Autism AND Diet.**” Clinical studies qualified for inclusion in our review of research studies that were then categorized as either supporting or having no effect on autistic symptoms.

Results:

Approximately 40+ studies have been conducted relating diet to autism, but they often lacked controls, used inconsistent measurable outcome tools, and/or were based on children with different ages or subject numbers. In summary, there were 8 studies each showing a benefit for casein-free/gluten-free diets and vitamin B6 plus magnesium (two neutral studies each). Three positive studies existed for vitamin B6 alone. Two studies each showing reduced autism symptoms (varied) existed for the gluten-free diet (two neutral), casein-free diet (one neutral), omega-3 fatty acids, and vitamin C. One positive study each existed for the ketogenic diet, folic acid (one neutral), magnesium, vitamin- mineral supplement, dimethylglycine (DMG) (one neutral), and probiotics.

Conclusion:

Although more placebo-controlled clinical trials are needed, the literature suggests that a subset of children with autism may benefit from a gluten-casein-free diet, along with vitamin B6-magnesium supplements (recommended Daily Intake (RDI) limit for age) under a physician’s care. We suggest that no one has combined the evidenced-based research linking autism and diet into one diet which is the

elimination diet. As a result, parents remain burdened with what diet to try first. Although the gluten-free and casein-free diets have been most extensively tested, the elimination diet that incorporates many of the diets utilized in practice has not been adequately tested to provide an evidenced-based diet for parents to initially give to their autistic children. We aim to test an elimination diet in children with autism which would allow parents to add foods back one at a time based on individual responses (study not yet funded or conducted).

Rosalind Picard

May 4, 2009

[Toward a voice for everyone by Rosalind W. Picard, Joel Smith, and Amanda Baggs](#)

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Karen Driscoll

May 4, 2009

[Karen Driscoll's presentation can be viewed here.](#) (PDF – 230 KB)